



# **The UK Human Genetics Commission**

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Secretary's Advisory Committee on Genetics Health and Society  
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## What is the Human Genetics Commission ?

- Formed in 1999 after UK biotechnology regulatory review and began a second term in January 2003
- Provides government with advice on the “big picture” on human genetics - in particular the ethical, legal and social implications of advances
- Members all appointed by open advertisement to reflect diverse viewpoints
- Work in public and aim to involve public at all stages of its work



## Who is on the Commission ?

- Chaired by Baroness Helena Kennedy QC. Vice-chair Professor Sandy McCall Smith
- ½ Science - clinical, research and commercial genetics
- ½ “Lay” - law, ethics, consumer, sociology and disability rights
- Representatives of the CMOs of England, Scotland, Wales and Northern Ireland and from HFEA





## What is the Commission's remit ?

- Analysis of developments in human genetics including:
  - impact on human health and healthcare
  - social, ethical, legal and economic implications
- Informing and consulting the public
- Promoting dialogue and collaboration
- Horizon scanning
- Advising on strategic priorities for research



## What has HGC done?

### *Reports*

- Inside information - a report on the protection of genetic information
- Genes direct - a review of direct genetic testing services
- MORI survey of attitudes to human genetics

### *Groups*

- Genetic Services subgroup with a UK wide focus
- New Monitoring Groups on public involvement, horizon-scanning research databases, gene patents and genetic discrimination and forensic uses of DNA
- HGC consultative panel of those affected by genetic conditions

### *Meetings*

- Information-gathering on insurance, pharmacogenetics, gene patents, stem cells, UK Biobank, reproductive choice
- Advising on the advisory and regulatory framework
- Overseeing developments in genetic testing



## A dialogue with the public

- Public involvement strategy
- Sets standards on openness, informing and consulting
- Openness is important but need 2 way communication - public engagement rather than public education
- Looking beyond the traditional methods - using interactive website, links with other groups and media outlets
- Recognise need to invest time and resources get it right





## HGC Consultative Panel

- Panel of 100+ people with direct experience of a genetic condition, including family members and carers
- Comments on draft reports, conclusions / options and priorities for future work
- Work mainly by correspondence, but attended introductory meeting (July 2002) and are invited to wider information-gathering seminars
- Very positive response from wide range of people has ensured a broadly representative panel which has already made useful contribution



## Genetics and Insurance

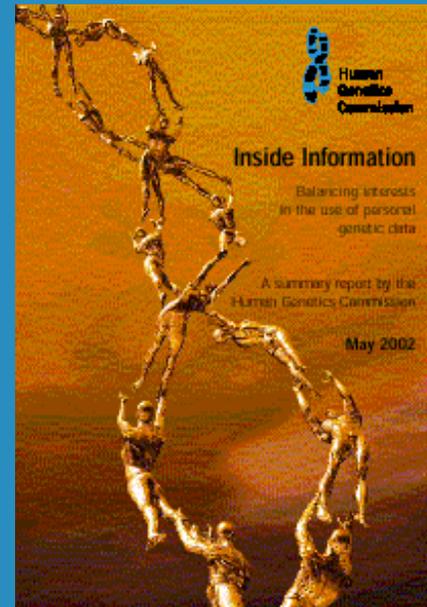
- HGC recommended a moratorium on use of genetic test results by insurers in 2001
- Welcomed the voluntary 5-year moratorium on disclosing results for policies less than £500,000
- Priorities for moratorium period:
  - Review the use of family history information;
  - Look at access to affordable insurance for those affected by a genetic condition e.g. Risk pooling
  - Promote openness about underwriting decisions and the information given to consumers; and
  - Consider wider regulatory and arbitration systems for genetic information and insurance



## Inside Information:

Balancing Interests in the Use of Personal Genetic Data

- May 2002 report followed “whose hands on your genes?” Consultation
- Large-scale consultation exercise resulting in responses from individuals and organisations.
- MORI poll, public meetings, asked the Consultative Panel for views.





## General Principles

- Balance between “respect for persons” and “genetic solidarity and altruism”
- Have drawn up principles based on overarching idea of the respect for persons:
  - Entitled to genetic privacy;
  - PGI should not be obtained without consent;
  - PGI should be treated as confidential; and
  - Entitled to genetic non-discrimination



## Key Recommendations

- New criminal offence to prevent deceitfully obtaining and analysing another person's genetic data
- Possible need for new UK legislation to protect people from unfair genetic discrimination
- Need to get the right balance between individual's interest in privacy and society's interests in benefiting from the use PGI for medicine or research





## Genetic Discrimination

- Opposed to genetic discrimination in all areas – employment, insurance, education and healthcare
- Public poll in 2000 showed genetic and insurance provokes a strong (negative) public reaction;
  - 78% disagree that insurance companies should be able to see genetic test results;
  - While 62% agree that genetic test results could be used for setting insurance premiums, only 8% think it should be used
  - Most concerns about life and critical illness insurance linked to house purchase
- HGC noted concerns about links between insurance and employment - pensions, annuities, ill-health retirement, critical illness, private healthcare



Human  
Genetics  
Commission

# Government White Paper on Genetics

- Policy statement on realising benefits of genetics via the National Health Service
- £50m investment in clinical laboratories, training and educating workforce, IT and R&D
- Safeguards and controls against inappropriate or unsafe use of developments in genetics
- Importance of HGC for debate, dialogue and advice

## Foreword by the Prime Minister



Our country has a remarkable scientific tradition. The extraordinary achievements of Newton, Darwin and a host of other visionary scientists have both greatly increased the understanding of our world and improved the quality of life for everyone.

Our success continues to be extraordinary: with just one per cent of the world's population, we receive nine per cent of scientific citations. Nowhere has this record been more notable in more decades than in bio-science and bio-technology.

The discovery in Britain of the structure of DNA, 50 years ago – perhaps the biggest single scientific advance of the last century – marked the beginning of a golden age of bio-science in Britain which continues today. It is likely to have as big an impact on our lives in the coming century as the computer had for the last generation.

The more we understand about the human genome, the greater will be the impact on our lives and on our businesses. As an increasing number of diseases are linked to particular genes or gene sequences, we will be able to target and tailor treatment better to offset their impact and even to avoid the onset of ill-health many years in advance.

I am proud to know that much of this ground-breaking work is already taking place in our country. I am also absolutely determined that the National Health Service should be able to respond to these advances so the benefits of genetics and the more personalised and improved healthcare it will bring are available to all.

It means we must prepare now for the future. We must invest in research and research facilities to drive further discovery. We must ensure the NHS has the skills and expertise to make best use of these advances. And we must also be ready to explain clearly and consistently to patients the new health care choices this will bring. Through the independent experts on the Human Genetics Commission we will ensure that people have access to advice about human genetics and the social and ethical issues involved. This is the best way of easing understandable public anxiety about the exciting revolution in health care.

This White Paper sets out how the Government intends to achieve all these goals. It also underlines our determination to ensure the NHS and its patients get the maximum benefit from the pioneering work already under way and the transformation it will bring in the delivery of health care in this country.

Tony Blair



## Government Response to *Inside Information*

Government has committed to:

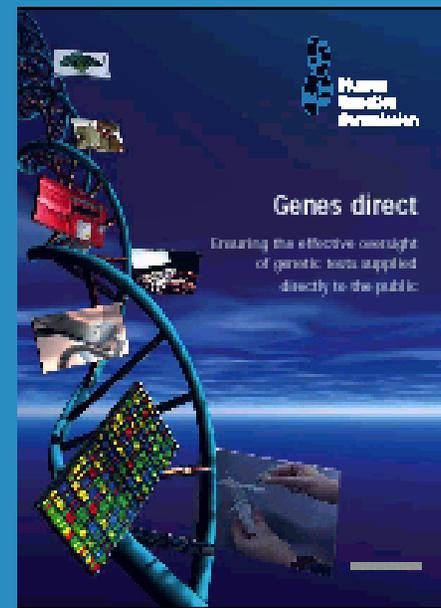
- Developing a new offence for non-consensual genetic testing
- Considering the evidence for unfair discrimination and the appropriate steps to take
- Welcoming HGC's input to a long term sustainable policy after the insurance moratorium
- Publishing a revised code of practice on patient confidentiality
- Police requests for access to UK Biobank to only be made 'in the most exceptional circumstances'



## Genes Direct:

Ensuring the Effective Oversight of Genetic Tests Supplied Directly to the Public

- Direct testing - especially via Internet - raises important issues
- New technology and knowledge may allow cheaper tests for carrier status, metabolism and family relationships (paternity)
- People increasingly want information about own health and freedom from normal constraints of GP appointments and consultant referrals
- People also feel strongly that vulnerable people should be properly protected against any commercial misuse of genetics





## Key Recommendations

- Stricter controls on direct genetic testing but do not believe there should be a statutory ban
- Predictive genetic tests that rely on home testing or home sampling should be discouraged
- Most genetic tests that provide predictive health information should not be offered as direct genetic tests
- There should be a well resourced NHS genetics service that can properly manage and allow access any new appropriate genetic tests



## Legal and Regulatory Framework

- Creation of MHRA as an opportunity to develop regulatory framework
- UK Genetic Testing Network introducing arrangements for reviewing tests
- Possible role for Human Tissue Authority
- Office of Fair Trading to be supported by improved professional standards
- Policing the internet - international consensus and better consumer education *“if it sounds too good to be true, it probably is”*



## Future HGC Work

- Genetics and discrimination - particularly with insurance and what happens after the moratorium
- Genetics and reproductive decision-making
- Short review of genetic paternity testing and services
- As outlined in genetics white paper - HGC to work with NSC to consider the case for offering genetic profiling of children at birth
- Ongoing monitoring role across the range of HGC topics

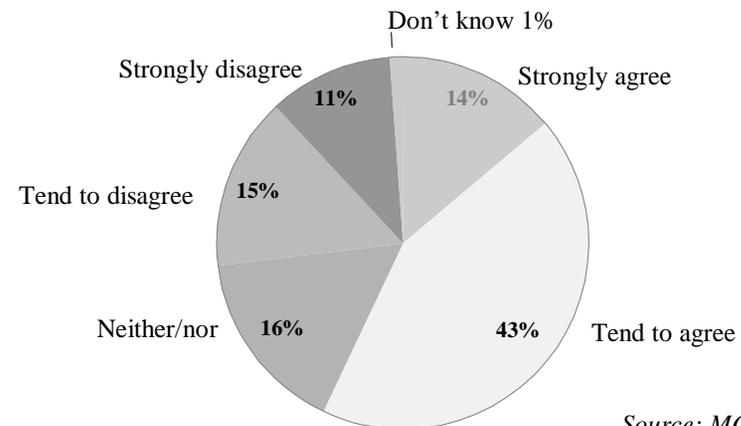


# Genetics and Reproductive Choice

- Identified as a priority for 2003/2004 and work underway
- Range of concerns across public - “eugenics” and “designer babies”
- New technologies driving screening and offer of testing
- Need to work with others - HFEA, NSC
- Continue discussion on PGD and PND

## Use of genetic testing

*Q33 Please tell me to what extent you agree or disagree ...  
Genetic information may be used by parents to decide if children with certain disabling conditions are born?*



*Base: All respondents (1,038)*

*Source: MORI*



## Summary

- HGC is now well established and respected
- HGC's role is to advise government on developments in human genetics and their implications for society
- It is doing this by:
  - Producing comprehensive reports on key issues
  - Promoting and participating in public debate
  - By working in an open and transparent manner ([www.hgc.gov.uk](http://www.hgc.gov.uk))
  - And working with others to seek socially sustainable policies